

Caring for someone with dementia

Organisations that can help



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**

Introduction

This booklet is for people caring for someone with dementia. Family and friends of someone with dementia may also find it useful.

This booklet provides a list of support organisations. There are contact details and a description of the services each organisation provides.

These organisations can offer a range of services and advice. These include:



practical care and support



housing advice



medical advice



legal advice



emotional support



financial advice

Most organisations listed provide free services. However, there may be some charges for some services. We have not listed commercial companies.

This booklet does not contain information on dementia symptoms, diagnosis or treatments. For information on these, please contact us for one of our free information leaflets.

This booklet was written in August 2014. It is due to be updated in August 2016. Please get in touch if you'd like a version with references or in a different format.

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What is dementia?

Dementia is not a disease itself, but a word used to describe a group of symptoms.

These can include:



The gradual loss of memory and communication skills.



A decline in the ability to think and reason clearly.



Difficulties in carrying out day-to-day activities.

Alzheimer's disease is the most common cause of dementia, affecting over 500,000 people in the UK. Other causes of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

We have separate information about each of these conditions, covering symptoms, diagnosis and treatment. Contact us if you'd like to know more.

Who is a carer?

A carer is anybody who looks after a family member, friend or neighbour who needs help because of illness, frailty or disability. All the care they give is unpaid, although they may be eligible for certain benefits. Anyone, of any age, can become a carer.

Many feel they are doing what anyone else would in the same situation - looking after their relative or friend. Usually, carers don't choose or plan to become carers. It can come suddenly out of a crisis, or it can be a role that develops slowly over time.

Care workers, support workers and personal assistants are distinct from carers. These are people who are paid for a specific service. This might be for domestic activities like cleaning or shopping, or help with personal tasks such as washing or dressing.

Caring for someone with dementia

Being a carer can cause a mix of feelings. It can be both rewarding and challenging. You may gain new skills, build closer relationships and be supporting someone you love. Caring can also be physically and mentally exhausting.

If you look after someone with dementia, you may have many questions and worries.

There is support for everyone affected by dementia, including people who look after someone with dementia. It's important to remember that you're not alone.

This booklet lists organisations that can help you find support and information – whether it's about the person you care for and the problems and worries you may encounter, or about you as a carer and the impact that caring has on your life.



Finding local support

Your GP should be able to help you with local sources of support, and many of the organisations in this booklet will also be able to help you find local contacts.

You can contact your local council or authority, which may have details of organisations in your community that can give help and support. As well as formal support services, there may be other activities in your area, such as befriending services, memory cafés or singing groups. Details of local groups like these can often be found in libraries and town halls.

Help from your local council, authority or Health and Social Services Trust

This is one of the first places to go for help. Everyone with dementia is entitled to an assessment of their needs and carers are also entitled to their own assessment. These might be called a ‘community care assessment’, a ‘care assessment’ or a ‘needs assessment’.

To arrange an assessment, call your local authority and ask to be put through to the Social Services office. If you live in Scotland, call your local council and ask for the Social Work Department; if you live in Northern Ireland, contact your local Health and Social Services Trust. A GP or hospital doctor can also arrange an assessment for you.

This assessment is to find out what help and support you need. This might be:

healthcare

equipment

access to day centres

help in your home

residential and respite care.

The local council must then provide services to meet those needs. However, each council has its own policy about what needs it will meet. This means services can vary across the UK.

The local council can charge for the services it provides. The person needing care will be financially assessed to see what, if anything, they can contribute. The council will provide you with a breakdown of how they calculate any costs.

Find your local social services or social work department contact number in the phone book or online at www.gov.uk/find-your-local-council



Sources of support - dementia-specific organisations

Alzheimer's Research UK

Alzheimer's Research UK offers free information on dementia. This includes information about Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. We have information on symptoms, diagnosis and treatments. We also run the **Dementia Research Infoline**. The Infoline can answer your questions about dementia research and help you to get involved in dementia research studies across the UK.



Alzheimer's Research UK
3 Riverside
Granta Park
Cambridge
CB21 6AD



0300 111 5555



enquiries@alzheimersresearchuk.org



www.alzheimersresearchuk.org

Dementia Research Infoline: **0300 111 5 111**
or email **infoline@alzheimersresearchuk.org**

- 9am - 5pm Monday to Friday
- UK-wide

Alzheimer Scotland

Alzheimer Scotland provides specialist services for people with dementia and their carers. They offer personalised support services, community activities, information and advice. The Scottish 24 hour **Dementia Helpline** can give information or emotional support on any issue to do with dementia.



Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh
EH3 7RN



0131 243 1453



info@alzscot.org



www.alzscot.org

Helpline: **0808 808 3000**
or email **helpline@alzscot.org**

- 24 hours, seven days a week
- Scotland

Alzheimer's Society

Alzheimer's Society provides information and services for people with dementia. They work in England, Wales and Northern Ireland. Local services include day care and home care for people with dementia. They can also provide support and befriending services to help partners and families. Their **National Dementia Helpline** can provide information, support, guidance and signposting to other organisations.



Alzheimer's Society
Devon House
58 St Katharine's Way
London
E1W 1LB



020 7423 3500



enquiries@alzheimers.org.uk



www.alzheimers.org.uk

Helpline: **0300 222 11 22**

or email **helpline@alzheimers.org.uk**

- 9am - 5pm Monday to Friday
- 10am - 4pm Saturday and Sunday
- A Live Online Advice service is available
9am - 12pm Monday to Friday on the website.
- England, Wales and Northern Ireland.

AT Dementia

This website has information about assistive technology for people with dementia. Assistive technology can be any device or system that helps someone perform a task. This includes devices like calendar clocks, automatic lighting and fall sensors.



www.atdementia.org.uk

Dementia UK

Dementia UK provides mental health nurses who specialise in dementia, called Admiral Nurses. They provide practical and emotional support to families affected by dementia. They can also provide advice on referrals to appropriate services and liaise with other healthcare professionals on your behalf. To find out if Admiral Nurses are available in your area, you can call their helpline.

The helpline and email service **Admiral Nursing DIRECT** gives advice and information about dementia. This is for carers, people with dementia and those worried about their memory.



Dementia UK
2nd Floor, Resource for London
356 Holloway Road
London N7 6PA



020 7697 4160



info@dementiauk.org



www.dementiauk.org

Helpline: **0845 257 9406**

or email **direct@dementiauk.org**

- 9:15am - 4:45pm Monday to Friday
- UK-wide

Guideposts Trust

Guideposts Trust provides services for people with dementia. They also provide an online dementia information resource called Dementia Web. This is to help people with dementia, their carers and health professionals find out about support and care services. For information about local dementia support services, call the **Dementia Web helpline**.



Guideposts Trust
Willow Tree House
Station Lane
Witney
Oxfordshire
OX28 4BH



01993 893560



gpt@guidepoststrust.org.uk



www.guidepoststrust.org.uk

Helpline: **0845 120 4048**
or email **info@dementiaweb.org.uk**

- 24 hours, seven days a week
- Scotland

Sources of support for people with specific forms of dementia

The Familial Alzheimer's Disease (FAD) Support Group

This support group is for families affected by familial Alzheimer's disease (FAD). The group offers information, advice and social opportunities for people with FAD and their families. For more information visit www.fadsupportgroup.org.uk or contact Jill Walton on jill.walton@ftdsg.org or **07592 540 555**.

The Frontotemporal Dementia Support Group

This support group is for carers of people with frontotemporal dementia (FTD). Carers may be coping with behavioural changes in a partner, family member or friend who has frontotemporal dementia. There is also a familial FTD support group which offers information and talks for those affected by genetic forms of the disease. Visit www.ftdsg.org for more information and local contacts or contact Jill Walton on jill.walton@ftdsg.org or **07592 540 555**.

The Lewy Body Society

The Lewy Body Society provides information and supports research into dementia with Lewy bodies (DLB). In partnership with Parkinson's UK, the Lewy Body Society provides advice and support to people affected by DLB, their families and carers.



Lewy Body Society
Hudson House
8 Albany St
Edinburgh
EH1 3QB



0131 473 2385



info@lewybody.org



www.lewybody.org

Helpline: **0808 800 0303**

or email **hello@parkinsons.org.uk**

- 9am - 8pm Monday, Wednesday, Friday
- 9am - 7pm Tuesday, Thursday
- 10am - 2pm Saturday
- UK-wide

The Posterior Cortical Atrophy (PCA) Support Group

The PCA Support Group is run through the National Hospital for Neurology and Neurosurgery in London. The group offers the opportunity to meet other people who have PCA and their carers, and they hold several meetings a year in different locations. Visit www.pcasupport.ucl.ac.uk for more information or contact Jill Walton on jill.walton@ftdsg.org or **07592 540 555** for details.

Primary Progressive Aphasia (PPA) Support Group

The PPA Support Group is also run through the National Hospital for Neurology and Neurosurgery in London. It offers people with PPA and their families the opportunity to meet and share their experiences. Contact Jill Walton on jill.walton@ftdsg.org or **07592 540 555** for more information.

The PSP Association

The PSP Association helps people with progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). It offers advice, support and information to people living with these conditions.



The PSP Association
PSP House
167 Watling Street West
Towcester
Northamptonshire
NN12 6BX



01327 322410



psp@pspassociation.org.uk



www.pspassociation.org.uk

Helpline: **0300 0110 122**

or email **helpline@pspassociation.org.uk**

- 9am - 5pm and 7pm - 9pm Monday to Friday
- UK-wide

YoungDementia UK

YoungDementia UK provides information, advice and support for people under 65 diagnosed with dementia, their family and friends.



YoungDementia UK
PO Box 315
Witney
Oxfordshire
OX28 1ZN



01993 776295



mail@youngdementiauk.org



www.youngdementiauk.org

Organisations for carers

All the organisations in this section offer help and advice on finding and paying for care, legal rights and support for carers, including respite care and benefits.

Care Information Scotland

Care Information Scotland is a telephone and website service. They provide information about care services for older people in Scotland. This service is funded by the Scottish government and run by NHS 24.

Helpline: **0845 600 1001**

Website **www.careinfoscotland.co.uk**

- 8am - 10pm, seven days a week
- Scotland



Carers Direct

Carers Direct provides a national helpline service for carers, providing confidential information and advice. This service is part of the NHS.



Carers Direct
PO Box 27079
Glasgow
G3 9EJ



0300 123 1053



www.nhs.uk/carersdirect

Helpline: **0300 123 1053**

Website: **www.nhs.uk/carersdirect**

- 9am - 8pm Monday to Friday
11am - 4pm Saturday and Sunday
- A webchat is available 9am – 6pm Monday to Friday on the website
- UK-wide

Carers UK

Carers UK provides advice and information to carers. This is available through the website, booklets, factsheets and **Carers UK's Adviceline**.



Carers UK
20 Great Dover Street
London
SE1 4LX



020 7378 4999 (Carers UK)
02920 811 370 (Carers Wales)
0141 445 3070 (Carers Scotland)
02890 439 843 (Carers Northern Ireland)



advice@carersuk.org



www.carersuk.org

Helpline: **0808 808 7777**

Website: **advice@carersuk.org**

- 10am - 4pm Monday to Friday
- UK-wide

Carers Trust

Carers Trust was previously The Princess Royal Trust for Carers and Crossroads Care. They provide access to breaks for carers, information and advice, education, training and employment opportunities.



Carers Trust
32-36 Loman Street
London
SE1 0EH



0844 800 4361 (Carers Trust UK)
02920 090 087 (Carers Trust Wales)
0300 123 2008 (Carers Trust Scotland)



info@carers.org



www.carers.org

Support for young carers

There are a number of websites providing help and advice for young carers. These include:



YC net (Carers Trust)
www.youngcarers.net



Young carers hub (NHS Choices)
www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx



Young carers (Barnardos)
www.barnardos.org.uk/what_we_do/our_work/young_carers.htm



Include programme (Children's Society)
www.youngcarer.com



Organisations for older people

Age UK

Age UK provides information and advice, services, products and training for older people. Local services can include: information, advice and advocacy services; day centres and lunch clubs; home help and 'handyperson' schemes; and IT and other training. The helplines can provide information and advice on all of these.



Tavis House
1-6 Tavistock Square
London
WC1H 9NA



0800 169 6565 (Age UK)
02920 431 555 (Age Cymru)
02890 245 729 (Age NI)
0845 833 0200 (Age Scotland)



via website



www.ageuk.org.uk

Helplines

England: **0800 169 6565** Wales: **0800 022 3444**

NI: **0808 808 7575**

• 8am - 7pm, seven days a week

Scotland: **0800 470 8090**

• 24 hours, seven days a week

Independent Age

Independent Age provides information and advice for older people, their families and carers. They focus on social care, welfare benefits and befriending services. The helpline can give advice on home care, care homes, NHS services and housing.



Independent Age
6 Avonmore Road
London
W14 8RL



020 7605 4200



charity@independentage.org



www.independentage.org

Helpline: **0800 319 6789**
or email **advice@independentage.org**

- 10am - 4pm Monday to Friday
- UK-wide



Organisations that
can help with
accommodation,
housing and
care homes

Relatives and Residents Association

The Relatives and Residents Association offers information and support to family and friends having to help their loved ones move into a residential home. They can also advise if you have concerns about care in a residential home.



Relatives and Residents Association
1 The Ivories
6-18 Northampton Street
London
N1 2HY



0207 359 8148



info@relres.org



www.relres.org

Helpline: **0207 359 8136**

or email **info@relres.org**

- 9.30am - 4.30pm Monday to Friday
- UK-wide

The Elderly Accommodation Counsel

The Elderly Accommodation Counsel helps older people make choices about housing and care. They run FirstStop Advice. This telephone service offers advice and information to older people, their families and carers about housing and care options.



Elderly Accommodation Counsel
3rd Floor
89 Albert Embankment
London
SE1 7TP



0207 820 1343



info@firststopadvice.org.uk



www.firststopadvice.org.uk

Helpline: **0800 377 7070**

or email **info@firststopadvice.org.uk**

- 9am - 5pm Monday to Friday
- UK-wide

Commercial care providers

There are a large number of providers of care and social services. Some of these providers will offer care through local councils as well as privately.

A good place to start looking for services is the Care Quality Commission. They are the care services regulator in England. There are equivalent regulators in the other countries of the UK. They publish reports on care homes and care services in the home (domiciliary care), which highlight the quality of care provided. You can search for local care services on their websites.

Care Quality Commission (CQC)



Care Quality Commission (CQC)
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA



03000 616161



enquiries@cqc.org.uk



www.cqc.org.uk

Care and Social Services Inspectorate Wales (CSSIW)



Care and Social Services Inspectorate Wales
(CSSIW)
Welsh Government Office
Rhydycar Business Park
Merthyr Tydfil
CF48 1UZ



0300 790 0126



cssiw@wales.gsi.gov.uk



www.cssiw.org.uk

Regulation and Quality Improvement Authority (RQIA)

(for Northern Ireland)



Regulation and Quality Improvement Authority
(RQIA)
9th Floor Riverside Tower
5 Lanyon Place
Belfast
BT1 3BT



02890 517 500



info@rqia.org.uk



www.rqia.org.uk

Care Inspectorate (for Scotland)



Care Inspectorate
Compass House
11 Riverside Drive
Dundee
DD1 4NY



0845 600 9527



enquiries@careinspectorate.com



www.scswis.com

General advice services

Citizens Advice

You can search on the main website for your nearest branch, or call one of the numbers below for details. Local branches should also be listed in your phone book. There is a self-help website for advice on subjects such as finance, benefits, legal rights and healthcare.



3rd Floor North
200 Aldersgate Street
London
EC1A 4HD



08444 111 444 (England/Northern Ireland)
08444 772 020 (Wales)
0808 800 9060 (Scotland)



www.citizensadvice.org.uk (England, Wales,
Northern Ireland)
www.cas.org.uk (Scotland)



adviceguide.org.uk



About us

Alzheimer's Research UK is the UK's leading dementia research charity funding world-class research to prevent, treat and cure dementia.

We help people to understand dementia and the progress we are making, as well as providing an opportunity for people with dementia and their carers to get involved in research.

There are many ways you can help us to defeat dementia faster. These include making a donation towards our pioneering research, volunteering to help at our events or with other initiatives, sharing your story to raise awareness or helping to review our health information. If you would like to find out more about how you can help us defeat dementia, contact us at the address on the back of this leaflet.

We are the UK's leading research charity aiming to defeat dementia.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



Contact us

Alzheimer's Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD



General enquiries

T: 0300 111 5555
E: enquiries@alzheimersresearchuk.org



Dementia Research Infoline

T: 0300 111 5 111
E: infoline@alzheimersresearchuk.org

www.alzheimersresearchuk.org



**Alzheimer's
Research
UK**

**The Power
to Defeat
Dementia**

Registered charity number 1077089 and SC042474

